

ARCH *State Respite Coalitions*

A COMPENDIUM OF FACT SHEETS
2011 UPDATE



November 2011

INTRODUCTION AND ACKNOWLEDGEMENTS

The effort to compile state respite coalition fact sheets began in 2008. Original fact sheets were updated and additional fact sheets were added each year, including 2011 for this document. Each fact sheet contains the following information on each state respite coalition:

- ➔ **Start-Up Process and Coalition History**
- ➔ **Structure**
- ➔ **Staff**
- ➔ **Funding**
- ➔ **Membership**
- ➔ **Meetings and Communication**
- ➔ **Major Activities**
- ➔ **Available Documents**
 - **Bylaws**
 - **Surveys**
 - **Strategic Plans**
 - **Brochures**
 - **Et cetera**
- ➔ **State Contact Information**

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

In addition, States are required to collaborate with State Respite Coalitions in implementing federal State Lifespan Respite Programs. These fact sheets can be used to educate Lifespan Respite partners as well. For information on State Lifespan Respite programs, which are primarily funded with state and federal funds through the US Administration on Aging, see <http://www.archrespite.org/lifespan-programs>.

Each state coalition is unique in structure, design, membership and in their activities. Most are focused solely on respite for family caregivers of all ages, but a few are broader in scope and promote caregiver issues more broadly. Nearly all are statewide and diverse, have an advocacy and oversight focus to promote respite at the state and federal level, 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 have direct involvement in helping to implement their State Lifespan Respite program, if they have one.

Fact sheets are included from the following states: **Alabama, Arizona, California, Colorado, Connecticut, Delaware, District of Columbia, Illinois, Indiana, Kansas, Louisiana, Maryland, Massachusetts, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Virginia, Washington State, and Wisconsin.**

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 also to Catherine Perrin who formatted the original document and to Maggie Edgar, Senior ARCH Consultant who compiled the fact sheets. We would also like to acknowledge the generous support from the **Jacob and Valeria Langeloth Foundation** who supported the original 2009 Fact Sheets Compendium and to the **Administration on Aging, US Department of Health and Human Services** for current funding support through the Technical Assistance Centers for Caregiver Programs and Lifespan Respite.

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STATE FACT SHEET

ALABAMA LIFESPAN RESPITE RESOURCE NETWORK

Start-Up Process and Coalition History

- In 2000, Alabama Council for Developmental Disabilities 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 \$150,000 three-year grant from the DD Council. UCP put together a task force of over 45 caregivers, disability organizations, faith-based staff and state agencies to develop a directory of respite services in Alabama. The task force was organized into four committees: funding, advocacy, public awareness and resources. The committees produced a strategic plan for Alabama to accomplish the goals of the grant. From the strategic plan, a project management plan emerged.
- The project was named Alabama Respite Resource Network (Alabama Respite). A document listing all available respite resources in our state was produced, a toll free number for caregivers to call for information and referral was established, and eventually a website was developed that allowed access by county to all known resources (www.alabamarespite.org).
- In 2003, after the introduction of the Lifespan Respite Care Act, Alabama Respite changed their mission to include caregivers across the lifespan.
- After the initial three year grant, from 2003-2006, Alabama Respite existed financially on UCP Huntsville fund raising dollars and small voucher respite and other grants that allowed Alabama Respite to continue to work toward passage of the Lifespan Respite Care Act and raise awareness and increase voucher respite funding in Alabama.
- In 2006, after significant state legislative education, Alabama Respite received a small line item in the 2007 state Education Budget. This 'stable' funding remains in jeopardy each year and advocacy efforts are required annually to maintain the funding.
- As Alabama Respite continued to grow, the need for additional staff became evident.
- In 2009, HJR 170 was passed by the Alabama Legislature establishing the Alabama Lifespan Respite Coalition. The Governor appointed key stakeholders including state agency commissioners, for- and non-profit organizations and consumers to serve on the Coalition.

- HJR 170 also named Alabama Lifespan Respite Resource Network as the state's lead entity for respite information and referral services.
- When the opportunity arrived to receive Federal grant monies as a result of the Lifespan Respite Care Act of 2006, Alabama Respite collaborated with the Alabama Department of Senior Services (ADSS) to become one of the first twelve states to apply for and receive Federal respite grant funds. At that time, Alabama Respite was able to increase project staff.

Structure

- Alabama Respite is staffed by the Director of Respite Services housed at UCP in Huntsville, and the Alabama Respite Program Manager, housed in Anniston. A part time Administrative Assistant coordinates a statewide voucher program, contracts and grants for additional voucher funding and assists with other activities related to our program. A fourth member of the staff was added by a grant from the Alabama Council for Developmental Disabilities for assistance with developing four **Sharing the Care** (STC) locations in south Alabama. The staff guides the Alabama Respite Coalition and it's three workgroups (Public Awareness, Education/Resources, Capacity Building) to not only accomplish the goals and objectives of Alabama Respite, but those of the Federal Lifespan Work Plan, as well.
- Alabama Respite is also responsible for administration of a voucher respite system for the Alabama Department of Mental Health that serves 600 caregivers of individuals with Intellectual Disabilities.
- A new volunteer initiative, **Sharing the Care**, has increased Alabama Respite's capacity by working with volunteer stakeholders within a localized geographic area to increase access to respite. The first of these initiatives began in Jefferson and Shelby Counties in December 2009, with the further locations developed in November 2010 in Montgomery, Mobile, Selma and Dothan. The intention of the **Sharing the Care** initiatives is to build a model lifespan system of district offices.
- We also manage a small, replicable community foundation grant to meet the respite needs of a gap population in one area of our state. Further local grants have been submitted to provide gap funding in communities throughout Alabama.
- A Faith-based Coalition was established in April 2011 to assist development of faith-based respite programs statewide.
- Alabama respite staff are members of three Veteran's Administration Caregiver Advisory Councils in Alabama.

Staff

- A Director of Respite Services, Alabama Respite Program Manager, Respite Grant Coordinator and Administrative Assistant complete the current staff.

Funding

- Current funding for Alabama Respite comes from a variety of sources that include: Lifespan Respite Care Program funds from Alabama Department of Senior Services; State of Alabama Education Budget as flow-through funding from Alabama Department of Rehabilitative Services; fund raising dollars from United Cerebral Palsy of Huntsville and Tennessee Valley, Inc., Alabama Respite's parent organization; Department of Mental health voucher respite contract funding; Alabama Council for Developmental Disabilities grant funds; and various additional small contract/grant projects.

Membership

- Thirty state agencies, organizations, and stakeholders, appointed by the Governor, make up the Alabama Lifespan Respite Coalition. Visit our website, www.alabamarespite.org to learn more about the Coalition membership and its duties.

Meetings and Communication

- The Alabama Lifespan Respite Coalition is tasked to meet at least twice yearly, although during the first year of the Lifespan grant, the coalition met four times, with one event held in October 2010 to celebrate Respite Awareness Month, National Hospice and National Family Caregiver Month. In addition to the general coalition meetings, each of the three workgroups usually meet between coalition meetings.
- **Sharing the Care** volunteers in Jefferson and Shelby Counties originally met monthly with committee meetings in between. Quarterly meetings of the general membership are advised, but the decision to meet is subject to the will or need within a specific **Sharing the Care** area. Committees also meet as needed to achieve goals or objectives of the group.
- Faith-Based Coalition meetings to date were held in April, May and June 2011.

Major Activities

- Collaborating with ADSS, which received one of first 12 federal Lifespan Respite grants
- HJR 170, establishing the AL Lifespan Respite Coalition, passed by Alabama Legislature in 2009
- Received state funding in 2006 with a small increase in 2011

- Maintains a website that receives over 1000 visits each month
<http://www.alabamarespite.org/>
- Worked with the Alabama Department of Child Abuse and Neglect, Children's Trust Fund (CTF) to replicate an existing voucher respite program throughout all Congressional Districts in Alabama
- Received support from six of seven Congressmen for passage of the Lifespan Respite Care Act
- Since 2007, administered contract funding from the Department of Mental Health to offer voucher respite to children and adults with developmental disabilities and/or mental retardation
- Since 1992, administered voucher funding from CTF of Alabama
- Piloted a project called **Sharing the Care** using the original Alabama Respite project management plan to develop respite resource networks, which has proven to be easily replicated in other locations throughout our state
- Hosted the 2007 National Respite Conference
- Performs multiple presentations statewide to hundreds of participants at state agencies, organizations and caregiver training events.

Documents Available (Bylaws, Strategic Plans, Surveys, Brochures)

- Brochures:
 - "Alabama Lifespan Respite Resource Network"
 - "Give me a Break"
 - "All About Our Special Family"
- Who Are The Caregivers Fact Sheet
- Caregiver Manual for hiring and maintaining a respite care provider
- Statewide Strategic Plan
- Statewide Project Management Plan
- Alabama Respite's Directory Survey hosted on our website
- Logo
- **Sharing the Care** Project Management Plan and related documents
- Voucher Respite Funding Documents
- HJR 170, establishing the AL Respite Coalition and naming the Alabama Lifespan Respite Resource Network as the state's lead entity for respite information and referral services.

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STATE FACT SHEET

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 very closely 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 who 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*, January 15, 2008; http://www.azcaregiver.org/PDF/Az_RespiteCare_Lifespan.pdf
- 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 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
- Arizona Caregiver Coalition (ACC) "officially" launched as part of the Governor's Conference on Aging held May 14-16 in Mesa, Arizona. The Lifespan Respite Care Network (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 Lifespan Respite Care Network (LRCN) held its first official meeting on June 4, 2008 at the Caregiver House of the Foundation for Senior Living.

Structure

- The Arizona Lifespan Respite Care Network (LRCN) functions as a focused network within the Arizona Caregiver Coalition.
- The LRCN leadership currently consists of three voluntary co-chairs.
- Three LRCN committees were established at the first meeting on 6/4/08, and currently those committees are engaged in activities set forth in Arizona's LRCP grant application, including working with a public relations firm on an awareness campaign for the LRCP and a new Respite Hotline. One of the committees will be focused on 2011 National Lifespan Respite Conference planning that will be held in Phoenix, Arizona.

Staff

- The Arizona Division of Aging and Adult Services Caregiver Specialist, assisted by the Respite Project Coordinator, currently performs the duties of the Lifespan Respite Care Specialist and acts as a liaison between the LRCN and state government.
- A part-time volunteer coordinator for the LRCN was hired by the AZ Caregiver Coalition in July of 2010, using the LRCP grant funds, to help setup and staff the new hotline and to help with national conference planning.

Funding

- Arizona's LRCP is currently funded by a grant from the US Administration on Aging's Lifespan Respite Care Program to the Arizona Division of Aging and Adult Services.
- Arizona still has a statute authorizing \$500K annually in state funding for the Arizona LRCP, but that funding is currently not available due to state's financial crisis.

- Future funding for the LRCN is expected to include support from stakeholders and others, and will incorporate grant writing, sponsorships, and possible support from the state-funded LRCP.
- LRCN financial support to date has come from the Arizona Family Caregiver Support Program and the Division of Aging and Adult Services, along with in-kind support from the Governor's Advisory Council on Aging.

Membership

- Statewide membership of service providers and caregivers from both the 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
- LRCN Newsletter starting soon and both the Arizona Caregiver Coalition (ACC) and the Lifespan Respite Care Network (LRCN) have websites that will eventually include forums, blogs, and downloadable information:
www.azcaregiver.org; www.azrespite.org

Major Activities

- Develop ACC charter and bylaws that will guide the LRCN
- Launch caregiver awareness campaign and respite hotline
- Plan and host 2011 National Lifespan Respite Conference and Lifespan Respite State Summit
- Advocacy to keep the statewide LRCP funded and able to continue to provide direct services

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Charter and bylaws under development
- Arizona Lifespan Respite Care Program Brochure
- University of AZ report: *Arizona Respite Care Throughout the Lifespan: Characterizing Unmet Needs*, University of Arizona, Jan. 2008;
http://www.azcaregiver.org/PDF/Az_RespiteCare_Lifespan.pdf

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STATE FACT SHEET

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 on October 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.
- The organization is currently looking toward hiring some paid staff to assist in its endeavors in the future.

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 the 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.calrespit.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 Californian respite services.
- 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 (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Articles of Incorporation and By-Laws
- Website: www.calrespit.org
- Minutes from CRA Meetings

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STATE FACT SHEET

COLORADO RESPITE COALITION (CRC)

Start-Up Process

- Colorado has been in the process of creating a Respite Coalition since 2000, when a small group of interested parties met to discuss CO's respite needs.
- 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).
- Two co-facilitators, Janis De Baca and Valerie Saiz, who are parents of persons with developmental disabilities, organized the first CRC meeting. They continue to facilitate the CRC and both work with families who have children with special needs in the Denver Metro area.
- The original impetus for the Colorado Respite Coalition 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 center-based respite model located in Ft. Collins, CO, called Respite Care Inc.
- This mission would eventually evolve into the current mission, which is to establish more extensive respite options for Colorado families. The underlying vision to create a "respite center" remains.

Structure

- The CRC utilizes both grassroots and professional organization approaches. It represents 75 professional organizations, and has a mailing list that includes over 300 parents and professionals throughout the state.
- CRC is a statewide organization. The Respite Coalition does not have regional or local chapters. The CRC is able to reach the entire state through community partners and participation from various organizations that work with the special needs population throughout the state.
- The Colorado Respite Coalition does not have 501(c)(3) status.

- The CRC does not have a Board of Directors, nor is it subsumed by another organization.

Staff

- The CRC has no paid staff.

Funding

- The CRC received a small grant in July of 2010 which allowed the co-facilitators to attend the Oct. 2010 National Respite Conference in Maryland and helped launch the website and a birth to 21 Colorado Respite Directory.
- The following organizations helped fund the development of the new website: Family Voices, the CO Dept of Public Health and the Environment, with in-kind support from the HCP offices at Denver and Tri-County Health Department.
- The CRC relies on in-kind donations.
- There is no state or private funding for a voucher respite program to help families access respite, although that is a goal of the CRC.
- The CRC has partnered with the Agency on Aging and Easter Seals Colorado. The Agency on Aging was awarded a National Lifespan Respite Care Grant in 2011. The grant would be used to further develop respite infrastructure and to initiate a voucher system for families.
- To date the CRC has not participated in any fundraising activities.

Membership

- Membership in the CRC is volunteer-based and there are no membership fees at this time. Members meet on a quarterly basis at the Daniel's Fund at no charge.
- There are over 300 members, including 75 organizations.
- Members include families, caregivers, state agency representatives, providers, advocates and employees of various organizations that provide services to the special needs population.

Meetings and Communication

- Meetings are held quarterly at the offices of a local non-profit foundation. Our quarterly meetings are open to everyone interested in supporting and expanding respite opportunities in Colorado.

Major Activities

- The CRC was a strong community partner in the start up of the “Discovery Clubs.” The Adventure Center in Alamosa, CO, was the initial model used to provide respite to families of children with special needs. Community college nursing students provided the bulk of the respite hours. This same model was then used by Easter Seals with support from community partners as they launched the first “Discovery Clubs” in the Denver metro in 2006. There are currently 5 such programs in the Denver metro area. Easter Seals provides the administrative, programming, and grant writing support, as well as training for the nursing students. They provide limited, but regularly scheduled, respite to over 450 children in 4 metro locations in 2009 - 2010, as well as providing respite to hundreds of children at the Easter Seals Camp in the Colorado mountains.
- Another outstanding member of the CRC has taken on the formalized training of respite providers, as well as the provision of limited respite funds for families. The Autism Society of Colorado (ASC) has a wonderful program called “Give me a Break” that continues to benefit many Denver families with members who have autism.
- The CRC developed and administered a statewide survey to families of children with special health care needs (CSHCN) to identify respite needs. Two hundred forty-four people responded to the survey and the Colorado Department of Public Health & Environment compiled the results into a power point presentation.
- In April of 2009 the CRC launched their own blog at (Coloradospite.wordpress.com)
- The CRC website was launched and includes the Respite Directory for families with CSHCN at www.coloradospitecoalition.org.
- 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.
- The CRC is able to reach the entire state through emails and participation from the Health Care Program for Children with Special Needs (HCP) network throughout the state. In conjunction with the Colorado Department on Aging, the CRC is exploring ways to expand its information systems.
- In April 2010 the CRC joined with the Chronic Care Collaborative (CCC) and the Colorado Agency on Aging (AoA) and Easter Seals Colorado with the goal of creating a more comprehensive/lifespan approach to respite in Colorado. As a result Colorado was awarded a Federal Lifespan Respite Care Grant in 2011. The new coordinator for this grant will be Ayesha Sharma.

- 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 (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Mission and Vision Statements
- Tri-fold brochures aimed at legislators, families and nursing schools
- Survey results

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STATE FACT SHEET

CONNECTICUT LIFESPAN RESPITE COALITION, INC.

Start-Up Process

- The critical need for respite was the most frequent and urgent need expressed by many families at a statewide Conference of Birth to Three Early Intervention providers and families of young children with special needs in 2000. This gave rise to a two-day Respite Forum in October 2001, which was held at the state Capitol in Hartford and drew over 70 families and agency representatives. The Conference was funded by a grant from the CT Council on Developmental Disabilities.
- The consensus of the forum participants was to establish a nonprofit corporation to address the inadequacies of respite availability in Connecticut.

Structure

- The organization was established to address the need for available respite for caregivers of persons of all ages and needs and was named *The Connecticut Lifespan Respite Coalition*, referred to as CLRC.
- In 2002, the organization was incorporated as a private nonprofit corporation, the Board of Directors and Advisory Committee were established, a Coordinator was hired, and brochure and information packets were developed.
- Volunteer members of the Board of Directors, in consultation with Advisory Committee members, refined and further defined the Mission, Vision, and structure originally drafted during the 2001 Forum.

Staff

- Staff had consisted of a paid Coordinator until 2008, when an assistant, bi-lingual coordinator was also hired to assist with a special 3-year project funded under contract with the CT Department of Public Health.
- The Coordinator currently implements an extended contract with the CT Department of Public Health. In addition to the assistant bi-lingual

Coordinator, the CLRC employs six regional contracted staff who work directly with families of children with special health care needs in facilitating the families' obtaining medical equipment as well as respite services.

- In 2010, CLRC hired a Project Administrator to assist with the state's implementation of a three-year Lifespan Respite grant received by the CT Department of Social Services from the U.S. Administration on Aging (AoA).

Funding

- The Coalition had originally been funded by grants from the CT Council on Developmental Disabilities. This funding was instrumental in helping CLRC continue to function effectively during its first years. Additional grants were obtained from private donor sources for special projects.
- A major source of funding has been through contracts with the CT Department of Public Health described above (note: these are contracts with the Department of Public Health, not grants).
- In 2009, CLRC received funding from the CT Department of Social Services through a Lifespan Respite grant from the U.S. Administration on Aging, as noted below.

Membership

- As determined in its initial formation, membership in the CT Lifespan Respite Coalition includes families, caregivers, agency representatives and providers, and advocates.
- Membership on the Coalition's Board of Directors and Advisory Committee aims to reflect this diversity of membership. It has recently been difficult to sustain full membership on the Board of Directors and the Advisory Committee. Among the reasons for this attrition is that coalition members have had to assume additional workload responsibilities in their own agencies, as well as other factors.

Meetings and Communication

- Meetings of the Board of Directors are held monthly. Meetings of the Advisory Committee are held quarterly, jointly with the Board of Directors meeting for that month. This was done to improve communication between the Board of Directors and the Advisory Committee.
- The Coalition Website, <http://www.ctrespite.org/> and a list serve for coalition members are facilitated by the Coordinator.
- The Coalition is currently developing a user-friendly database with information listing statewide agencies offering respite and other services. The

data are organized regionally, according to those regions of the state serviced by each of the Aging and Disability Resource Centers. The objective is to improve the uniform coordination of information and to foster greater accessibility to respite for caregivers of persons of all ages.

Major Activities

- CLRC is partnering with the CT Department of Social Services and Aging and Disability Resource Centers (ADRC's) to implement Lifespan Respite grant received by the State Dept. of Social Services. Objectives of this grant include improving statewide coordination and access to quality respite care services for persons of all ages. Connecticut was one of twelve states awarded such grants in 2009.
- The Coalition has provided workshops for family caregivers regarding respite and the different ways to find alternative, temporary care.
- A book called "Get Creative About Respite" was written by the Coalition's Education Subcommittee, in consultation with members of the Board of Directors and Advisory Committee, for use during these workshops. The book provides advice and checklists for caregivers, offers ideas on how to evaluate potential caregivers/respite providers, which the family hires independently, and has pages, which can be easily replicated to update personal information as the needs of the person requiring care change. A copy of the book is given to each family caregiver attending the workshops. The book continues to be printed and disseminated at numerous state conferences through contracts with the Department of Public Health.
- Originally written for families providing ongoing care to children with special health care needs, the book is now being adapted for use by caregivers of persons of ALL AGES. Members of the Board of Directors are currently making these adaptations
- Currently, the CLRC has again contracted with the Connecticut Department of Public Health to implement a Medical Home Initiative Contract for services, including financial and equipment assistance, to families who have a child with special medical needs. The Coordinator for the Coalition continues to implement this contract.
- The Coalition has updated Connecticut's Infoline Respite Resources Inventory and is expanding the Coalition's database to provide additional information about respite resources according to regions of the state served by each of the Aging and Disability Resource Centers. This expansion is one aspect in the implementation of the AoA grant to Connecticut.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Brochures
- By-Laws
- Strategic Planning Goals
- A guidebook for family caregivers, *Get Creative about Respite*, can be downloaded free at www.ctrespite.org.
- Committee Descriptions
- Website: www.ctrespite.org

State Contact Information:

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Prepared in 2011 by the Connecticut Lifespan Respite Coalition. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org

STATE FACT SHEET

DELAWARE CAREGIVERS SUPPORT COALITION

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. Subcommittees have been established to address issues raised by the Advisory Committee such as Outreach, Sustainability, and Financial Assistance.

- The Delaware Lifespan Respite Care Network is part of Easter Seals Community Outreach Program which is also a Caregiver Resource Center, provides Support Services for the state's ADRC, and manages the state's Low Interest Loan Program for assistive technology.

Staff

- Funding from grants currently pays for two part-time positions: a project manager and project coordinator both located at Easter Seals.

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.
- 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 about \$500,000. The foundations include Delaware Community Foundation, Longwood Foundation, and Welfare Foundation. The grants provide funding from 2009 through 2011. The funding pays for administration as well as respite vouchers.
- The Coalition has established a Sustainability Subcommittee, which has developed a plan for ongoing fundraising activities.
- The Sustainability Committee is meeting with representatives of state agencies to work toward sustained state funding for the network's infrastructure. A matching challenge grant from the Longwood Foundation is providing incentive for state agencies to commit to matching dollars.

Membership

- Members of the Coalition represent a broad spectrum of stakeholders interested in the issue of respite care including caregivers and consumers, service providers, and state agencies. The members provide representation that is statewide, and across ages and disabilities. A list of the membership can be found at www.delrespite.org. There is no membership fee.

- Two recent Respite Summits held in March 2010 and April 2011, provided impetus for inclusion of additional interested parties who have been invited to participate in subcommittees.

Meetings and Communication

- The Advisory Committee meets quarterly, face-to-face, to provide input and guidance for the Network. 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. Subcommittees meet face-to-face several times a year, with the option of attending by phone.
- 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 Delaware Lifespan Respite Care Network 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, and 2) help with paying for respite care services through grants to families of up to \$500 per year per care recipient.
- For the last two years the DLRCN has sponsored Lifespan Respite Summits. 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 over 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.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Information about the Coalition and Network can be found at 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*.

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STATE FACT SHEET

DISTRICT OF COLUMBIA LIFESPAN CAREGIVING AND RESPITE COALITION

Start-Up Process

- The DC Lifespan Caregivers and Respite Coalition (DCLCRC) 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. DCLCRC supports agencies and organizations that help caregivers across the lifespan maintain their own health and well being while providing optimal care.
- The District of Columbia Lifespan Caregiving and Respite Coalition (DCLCRC) started in September 2010 as a result of the DC Office on Aging receiving 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 founding members of the coalition were representatives from DC agencies that serve aging citizens and citizens with disabilities or fund respite care services as well as grantees of the DC Office on Aging.
- 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

- The DCLCRC leadership and staff support is currently being provided by the staff of the DC Caregivers Institute and the DC ADRC. The DC ADRC hosts and sponsors all Coalition activities. The goal is to transfer leadership to a non-governmental member that can apply for grants to sustain the program after the federal lifespan respite monies end.
- There are two working committees for the coalition: the lifespan caregiving workgroup and the lifespan respite workgroup. Both groups are charged with identifying gaps in services and resources and bringing recommendations for action to the coalition. Each group is also tasked with completing appropriate activities.
- The Lifespan Respite Workgroup also serves as the advisory committee for the DC Lifespan Respite Program.

Staff

- The program operates with a 16 hour a week Program Analyst staff position.
- The DC Caregivers Institute provides staff support for one day a month to prepare for the meetings.

Funding

- The DCLCRC is funded completely by a grant provided from the US Administration on Aging to the DC Office on Aging.

Membership

- Membership in the DCLCRC is free.
- Membership includes representatives from aging, children 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.

Meetings and Communication

- During the first six months, the coalition met once a month in person. Due to limited parking in DC, the group requested that we meet monthly by conference call. Staff is investigating convenient locations for quarterly face to face meetings. All other communications are done by email and telephone.

Major Activities

- Received funding FY '10.
- 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 suspected respite providers to verify their operations; 62 agencies responded to the survey. A respite care listing

was created from this information. 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 weekly chat sessions for caregivers about respite care.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- DC Respite Care Provider Survey
- Program Brochure
- Consumer Tips for Quality Respite brochure
- Operating Procedures
- Focus Group Reports
- Chat Line
<http://dcoa.dc.gov/DC/DCOA/ADRC/Lifespan+Respite+Care/Chat+Live>

State Contact Information:

Aging and Disabilities Resource Center
Washington, DC
(202) 535-1444

Prepared in 2011 by the Delaware Caregivers Support Coalition. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org



STATE FACT SHEET

ILLINOIS RESPITE COALITION

Start-Up Process

- More than a decade ago, the Illinois Department of Children and Family Services (DCFS) received federal funding through the Temporary Child Care for Children with Disabilities and Crisis Nurseries Act (TCCA) to develop six demonstration grants across the state to fund crisis nurseries and respite programs.
- The Illinois Respite Coalition (IRC) started out as a grassroots organization in 1998 by a group of parents, concerned respite providers, state agencies and national leaders who came together to address the desperate needs for respite services.
- Technical assistance was provided by the ARCH National Respite Resource Center to help establish the coalition.
- In September 2006, the IRC hired a full-time Statewide Respite Coordinator with a grant awarded by DCFS. The IRC was created primarily for advocacy work –educating legislators and the public about the need for respite.
- The organization now focuses on ensuring respite care is provided with safety, quality and access in mind. In 2008, new board members joined the coalition and a new agency stepped forward to serve as the fiscal agent.

Structure

- The IRC has a Board of Directors that serves as leadership for the coalition and as advisors to the coalition's paid Statewide Respite Coordinator.
- A private, non-profit organization serves as the fiscal agent and provides in-kind staff support.
- The IRC has bylaws, a budget, and a program plan that was created to carry out a grant from the Department of Children and Family services (DCFS).

Staff

- The Statewide Respite Coordinator is the only paid staff position under the IRC's direction.
- IRC members serve as volunteers.
- The IL Lifespan Respite Program, administered by the Illinois Department on Aging with a grant from the US Administration on Aging, has a Lifespan Respite Program Director, Lifespan Respite Program Supervisor, and Lifespan Respite Program Assistant who interact with the IRC to ensure that the work plan for the Lifespan Respite grant in Illinois is carried out.

Funding

- The Statewide Respite Coordinator is currently funded through a continuing grant from DCFS. Marklund, a non-profit organization, serves as the Illinois Respite Coalition's fiscal agent and provides additional in-kind support.
- Membership Dues
- Funding from the Illinois Dept on Aging's Lifespan Respite Grant
- In-kind donations

Membership

- The organization depends on its membership for networking, referrals, advocacy and funding. Written membership policies and benefits are available. Dues are required. The IRC offers members:
 - Conference Discounts
 - Respite Referrals
 - Quarterly E- Newsletter
 - Listing on website
 - Provides advocacy support
 - Offers summit discounts
 - FREE booth at the summit
 - Resources about legislation and funding opportunities
 - A Respite e-newsletter
 - FREE quarterly trainings
 - Lists Members as EXPERTS in the field of Respite Care and provides membership list to media (TV, Print, Radio, Broadcasts, Website Hosts, Etc.) as needed.

Meetings and Communication

- The IRC Board of Directors meets six times each year.

- Quarterly membership meetings and trainings are offered.
- Illinois Respite Coalition's Annual Respite Summit offers networking opportunities.
- On-going communication is provided through a listserv and website www.illinoisrespite.org

Major Activities

- Lifespan Respite Grant was awarded in 2009 to the Illinois Department on Aging (IDoA). The IRC partnered with the IDoA to help carry out the work plan. The IRC, in partnership with IDoA, will provide a coordinated system of accessible, community-based respite services for caregivers and individuals regardless of age, ethnicity, special need, or situation.
- The IRC provides services to any family caregiver or provider in the state of Illinois needing information, resources and training relative to Lifespan Respite.
- 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.
- Annual Summit. Each April, IRC hosts an Annual Respite summit. Agencies, families and state representatives are invited to learn about the importance of respite care in the state and how current work will ensure accessibility for respite services for all families.
- Respite Day. An annual Respite Day is put forth for all families in the community caring for an individual with special needs.
- A website was developed in early 2009 at www.illinoisrespite.org.
- Established Emergency Respite Criteria to disburse Respite Funds to families in an unforeseen/unplanned circumstance through the Federal Lifespan Respite Grant.

Documents/Resources Available (*Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies*)

- Bylaws
- Policies and Procedures Manual
- Brochures
- Membership information
- Newsletter

- Surveys
- Strategic Plans
- DCFS program Plan
- IDoA Program Plan
- Job description of Statewide Respite Coordinator

State Contact Information:

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Prepared in 2011 by the Illinois Respite Coalition. For more information, contact Jill Kagan, ARCH at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org



STATE FACT SHEET

INDIANA RESPITE COALITION (IRC)

Start-Up Process

- The director of Agape Respite Care, Inc., a private nonprofit lifespan respite service and the assistant director with the Division of Disability and Rehabilitative Services (DDRS) Bureau of Developmental Disabilities Services (BDDS) met in December of 2007 to develop a state respite coalition. A list of key stakeholders was developed and invitations were sent. The first meeting of the Indiana Respite Coalition (IRC) was held in January 2008.
- The charter members include a consumer, three parents, and representatives from the following organizations: ARC of Indiana, INARF, United Cerebral Palsy of Indiana, NAMI, Division of Disability & Rehabilitative Services, Division of Aging, Easter Seals ARC of N.E. Indiana, Community Ventures in Living, Sycamore Services, Bethesda Lutheran Homes & Services, and Agape Respite Care, Inc.
- There has been little activity in 2011. The annual face-to-face meeting in the Spring was cancelled due to lack of interest.

Structure

- IRC was designed to be statewide from the beginning
- The plan was to form chapters in each district that has an Aging and Disability Resource Center (ADRC). This would result in 16 chapters and cover the entire state.
- The coalition was established by a group of 15 charter members, with two members serving as co-chairs of the IRC. Membership was opened up to others following the First State Summit in July 2008.

Staff

- There is no paid staff. Executive board members serve as volunteer staff.

Funding

- Some initial funding was supplied by the Indiana State Division of Disability and Rehabilitative Services.

- In-kind services from various agencies represented by the Charter Members have assisted in the development of the IRC.

Membership

- A membership form was developed.
 - Individual/Family membership is \$10/year
 - Professional/Organizational membership is \$50/year
- Very few members pay dues
- 35-50 attend the annual respite meeting held at the Government Center in Indianapolis in the Spring (the meeting was cancelled in 2011)
- Most members are respite providers or agency representatives, some case managers and a few families and family caregivers.
- The Indiana Division of Aging and the Division of Disabilities and Rehabilitative Services have declined participation recently, stating they feel activities of the coalition present a conflict of interest for them.
- The ARC and UCP of Indiana are represented

Meetings and Communication

- IRC Charter members meet every other month by conference call and once a quarter face-to-face.
- The Executive Committee last met in August 2011.
- There is usually an annual meeting once a year at the Government Center in Indianapolis in the Spring, however none was held in 2011.
- Information is posted on the website <http://www.in.gov/fssa/ddrs/3690.htm>

Major Activities

- The first Indiana Lifespan Respite Summit was held on July 9, 2008 at the Government center in Indianapolis. Guest speakers included: Senator Dennis Byars of Nebraska, Jill Kagan, chair of the National Respite Coalition and Phyllis Stephenson of the North Carolina Respite and Crisis Care Coalition.
- The second summit was held in April 2009 and the third in April 2010.
- A web site has been developed and a toll free number released.
<http://www.in.gov/fssa/ddrs/3690.htm>

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Bylaws
- Mission statement
- Vision statement
- Membership form
- Website: (see above)

State Contact Information:

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STATE FACT SHEET

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 to help guide our efforts. Result of the summit was formation of the Kansas Lifespan Respite Coalition.
- 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 and an active member currently serve as Co-Chairs.

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, etc.

Funding

- The KLRC wrote a grant in 2008 and received approximately \$12,000 in funding. Purposes of the grant are to assist the coalition with community engagement and organizational development.

- The KLRC wrote the same grant in 2010 and received approximately \$11,000 in funding for program development and revenue development.
- The KLRC does not charge dues for membership.

Membership

- The KLRC currently has approximately 40 members. For a list of current members, see 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 has met every 2-3 months since the statewide summit in 2007. 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 KS Senate Ways and Means Committee in March of 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 the fall of 2008 to bring statewide membership together to continue organizational development and focus on initiatives.
- Using grant funding, the KLRC launched a website (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.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- KLRC Mission Statement: The mission of the KLRC is to promote access to and use of respite for all Kansas caregiver, through community awareness, advocacy, education, and collaboration by providing a statewide respite care system.
- Website: www.ksrespite.com
- KLRC Membership Application

- KLRC Meeting Minutes
- Statewide Respite Survey

State Contact Information:

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STATE FACT SHEET

LOUISIANA COALITION

Start-Up Process

- The Coalition began in 2009 in response to the economic needs of health-related expenditures related to long-term care throughout the state. This group of stakeholders recognized a need to develop a more organized and cohesive approach to recognition of informal caregivers who provide more than 600 million hours of unpaid care annually in the state.
- The Department of Health and Hospital's Office for Aging and Adult Services, in conjunction with collaborating agencies, submitted a planning grant proposal requesting federal grant funds. The funds were requested to explore lifespan respite needs and develop a foundation for how resources will be shared to provide respite services throughout the state.
- In late 2011, a part-time program director was hired to lead the respite planning efforts.

● *Structure*

- The Louisiana Lifespan Respite Coalition is managed from within Louisiana's Department of Health and Hospitals Office of Aging and Adult Services.
- The Coalition is currently in the process of expansion and has a specific matrix of needs to fill, which include but are not limited to care recipients and care providers and past care providers. Community representatives, state officials, and interagency representatives are also among those listed as stakeholders in the development and execution of the Coalition.

Staff

- A paid part-time Director of the Respite Project supervised by a Program Manager for the Office of Aging and Adult Services for the Louisiana Department of Health and Hospitals, recruits, manages, and develops resources for the state related to respite services.

Funding

- The Louisiana Coalition's part time Director and the Office of Aging and Adult Services staff positions and expenses related to the generation of resources, materials, and development of the coalition are funded by a Lifespan Respite grant. This project was begun in 2011.
- Membership dues, fundraising, special events, estate planning, and additional caregiver/care recipient support will be pursued once the Coalition is developed more fully.

Membership

- Louisiana Lifespan Respite Coalition members represent not for profit, government and for-profit entities. Membership on the coalition is to be statewide.
- Criteria for inclusion as a member of the statewide respite coalition is currently being evaluated and determined. At present, the Coalition matrix of needs has been re-launched.

Meetings and Communication

- Meetings are held in the regions quarterly. Additional individual coalition recruitment meetings are held between the Program Director and different persons involved or interested in being involved in the creation of a statewide lifespan respite project.
- The Louisiana Lifespan Respite Coalition hosts phone conferences to address topics and needs of the group.
- The Louisiana Lifespan Respite project will communicate by website through the Office of Aging and Adult Services website hosted by Department of Health and Hospitals. This is currently under development and slated for launch as of January 2012.

Major Activities and Scheduled Activities as Coalition Develops

- Assist State Health Department with incorporation of respite as a benefit under the state's programs and/or promoting the service added to the waiver recently.
- October – November 2011– First Louisiana Lifespan Respite Months Governor's Proclamation
- October 2012 –Lead an interagency videoconference on Lifespan Respite Options
- Launch an Active Membership Drive in all three regions of the state

- Website/Meeting minutes and up-to-date information with links to agencies
- Pilot Voucher Funding program or related respite project that will bring together communities
- Louisiana Lifespan Respite Coalition Training offered by ARCH
- Participation in national respite conferences and networking/consulting with other states on lifespan respite issues

Documents/Resources Available

- Mission Statement
- Older Americans Month Fact Sheet
- Disability Awareness Fact Sheet
- Needs Assessment
- Community Provider Survey Responses
- *Caregiving Costs Someone/Respite Rewards Many*

These may be obtained by contacting below or visiting website on or around January 2012 at www.dhh.org search for: OAAS or Respite

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Prepared in 2011 by the LA Lifespan Respite Program. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org



STATE FACT SHEET

MARYLAND RESPITE CARE COALITION, INC. (MRCC)

Start-Up Process

- Began with a \$500 Seed Grant from ARCH in 1997 to hold statewide Respite Awareness Day with focus on Lifespan Respite and creating a Statewide Respite Coalition
- First Annual Respite Awareness Day Conference held September 1998 with over 300 in attendance
- Public and private agencies represented:
 - Child Welfare
 - Developmental Disabilities
 - Mental Health
 - Aging
 - Adult Protective Services
 - State legislators, etc.
- Began a Strategic Planning Process in spring through fall of 1999
- Became a 501(c)3 in June 2000

Structure

- Board of Directors – 7 to 15 member Board as established in By-Laws
- Committees – Fund Raising Committee, Membership Committee, Annual Conference Committee, Advocacy and Education Committee and Public Relations/Public Policy Committee

Staff

- All volunteers

Funding

- Membership Fees (see below)
- Fund Raising
- Collaborative partnerships with private and public organizations for staff time and gifts of respite.

Membership

- 2011 membership consists of individuals and organizations and represents diverse entities from across the lifespan and across disability groups.
- Individual and Organizational Membership Fee Structure
 - Annual membership fees for individuals are \$20
 - Annual membership fees for organization are \$85
 - Other levels of giving are offered

Meetings and Communication

- Board meets six times a year: January, March, May, July, September and November
- Committees meet throughout year
- Email Group
- Annual One-Day Conference

Major Activities

- Annual Statewide Respite Awareness Day Conference – Fourth Monday in October since 2nd Annual Conference\
- Helped enact legislation to establish the first State-sanctioned Caregivers Coordinating Council
- Only organization to be named in state legislation to be a member of the Maryland Caregivers Support Coordinating Council. (An Advisory Council to the Governor and General Assembly)
- Annual Fund Raiser
- Presentations, exhibits and other outreach activities as schedules permit
- Legislative Advocacy
- Information and Referral
- Hosted 2010 National Lifespan Respite Conference in Baltimore, MD

Documents/Resources Available (*Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies*)

- By-Laws
- Articles of Incorporation
- MRCC Membership Brochure
- Conference Brochures

- National Conference Organizing Materials
- Website: www.respitecoalition.org

State Contact Information:

(240) 453-9585

www.respitecoalition.org

Prepared in 2011 by the Maryland Respite Care Coalition, Inc. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org



STATE FACT SHEET

MASSACHUSETTS 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. The coalition was incorporated as a 501(c)(3) organization and met regularly for a few years before becoming less active.
- In 2009, a planning group was convened in order 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 the spring of 2010.
- Massachusetts was awarded a Lifespan Respite Care Grant in Sept. 2010.

Structure

- At this time, the structure is informal. Membership is both grassroots and professional and has statewide representation. The coalition is free standing at this time.
- At this time there is one statewide group with no regional/local chapters.
- There are several active subcommittees: Needs Assessment, Training, Website Development and Event Planning.

Staff

- Half time project coordinator is funded through the Lifespan Respite Grant.

Funding

- At this time all donations of staff time and materials have been in-kind.

Membership

- The Coalition currently has approximately 90 member organizations and individuals representing a range of ages, conditions and family circumstances. Several family caregivers are members of the coalition, as are representatives of all relevant Massachusetts state agencies.

- As the Coalition develops over the coming year, a membership fee structure will be considered. We will continue to conduct awareness campaigns and engage in other efforts to increase membership in the Coalition.

Meetings and Communication

- Quarterly coalition meetings are held. The location varies in order to encourage participation across the state.

Major Activities

- Needs assessment activities have been a major focus in 2011. We have recently released an online Family Caregiver Respite Needs Survey. We are also conducting Key Informant Interviews and Caregiver Focus Groups. We will be surveying providers shortly as well.
- A coalition website is currently in development and should be online soon.
- A Caregiver Awareness Event is scheduled for November 2011.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Fact sheet, brochure and Family Caregiver Survey are available upon request.

State Contact Information:

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Prepared in 2011 by the Massachusetts Respite Coalition. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org

STATE FACT SHEET

MINNESOTA LIFESPAN RESPITE LEADERSHIP GROUP

Start-Up Process

- The Minnesota Lifespan Respite Leadership Group was established as an outcome of the statewide Lifespan Respite Summit that was convened in March 2010.
- The Leadership Group initially came together to apply for a grant under the Lifespan Respite Care Act of 2006 and to explore the possibilities of establishing a more permanent coalition.

Structure

- The Leadership Group is currently an informal group of partners who are committed to working together to improve respite services across the lifespan.

Staff

- Staff support is provided, with funding from the AoA Lifespan Respite Grant, by the Minnesota Board on Aging.

Funding

- AoA Lifespan Respite Grant (Sept. 2010 – Sept. 2013)

Membership

- Membership is open to all who are interested. Currently members include family caregivers, lifespan respite and caregiver service providers, advocacy organizations and state agencies.

Meetings and Communication

- The Leadership Group holds quarterly in-person meetings. Some members may participate by conference call.
- Agendas and minutes of meetings are distributed by email. Announcements and other communication documents are distributed through the Leadership Group by email.

Major Activities

- In November 2010, the Transform 2010 Forum was convened by the MN Board on Aging and the Departments of Human Services and Health to recognize the culmination of a five year long project called Transform 2010. The large public forum included a policy discussion regarding lifespan respite.
- In April 2011, the Leadership Group conducted a webinar titled "Help Family Caregivers Find Your Services Online." The target audience was respite providers across the state. The goal of the webinar was to engage these organization in improving the service listings in Minnesota's online service database, www.minnesotahelp.info and identify additional strategies to better reach family caregivers.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- The Leadership Group has been analyzing the service listings in www.minnesotahelp.info in an effort to improve this information and make it easier for family caregivers to access respite services. Information related to this analysis is available upon request.
- The Leadership Group is also assessing current state agency programs that provide respite to family caregivers across the lifespan. Information related to this assessment is available upon request.

State Contact Information:

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Prepared in 2011 by the Minnesota Lifespan Respite Leadership Group. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org

STATE FACT SHEET

MISSOURI LIFESPAN RESPITE COALITION

Start-Up Process

- In February 2010 a group of interested persons from across the state came together for the first time to finalize plans for the Missouri Lifespan Respite Summit.
- On March 24, 2010, a Missouri Lifespan Respite Summit was held. Individuals interested in family caregivers from all populations along the lifespan were represented.
- On April 19, 2011 interested persons from across the state attended an organizational meeting to adopt a Mission Statement and By-laws for the Missouri Lifespan Respite Coalition.

Structure

- April 19, 2011, a Mission Statement and By-laws were adopted.
- On September 16, 2011, the Missouri Lifespan Respite Coalition voted on and accepted the Interim Board of Directors to serve until April 2012.

Staff

- The Missouri Lifespan Respite Coalition does not have paid staff.

Funding

- The Missouri Lifespan Respite Coalition does not have funding.

Membership

- Our membership is comprised of families, caregivers, state agency representatives, Silver Haired Legislature, providers and employees of various organizations that provide services to the population of all ages.

Meetings and Communication

- The Missouri Lifespan Coalition meets quarterly, and two of those meetings are face to face in April and September. Conference calls are utilized for other meetings.
- Committee meetings are done more frequently, as determined by the committee chair, to exchange ideas and facilitate sharing of ideas and work assignments.
- Our current committees include the Governance Committee, Legislative Committee, and Marketing and Outreach Committee.

Major Activities

- The Marketing and Outreach Committee is currently working on a brochure and strategies to bring more members to the coalition.
- At our April 2012 meeting the coalition will elect a new Board of Directors.

Documents/Resources Available (By-laws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Mission and Adopted By-Laws

State Contact Information:

Interim Co-Chair #1 Lavonne (Bonnie) Stigall
Support Service Manager
Northwest Missouri Area Agency on Aging
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Prepared in 2011 by the Missouri Lifespan Respite Coalition. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org



STATE FACT SHEET

MONTANA STATE LIFESPAN RESPITE COALITION

Start-Up Process

- Held a Lifespan Respite Summit in March 2011 to address respite needs, gaps and current use
- Formed a group of interested parties to be coalition members
- Wrote a grant for a Lifespan Respite Grant

Structure

- Not available yet

Staff

- None yet

Funding

- To be decided

Membership

- Open to consumers, providers, agency representatives and other interested parties

Meetings and Communication

- Quarterly WebEx meetings and one annual meeting in person
- Communication through email and phone

Major Activities

- Focus groups

- Public Relations
- Will be creating a website
- Looking at long-term sustainability

Documents/Resources Available (By-laws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Not available yet

State Contact Information:

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STATE FACT SHEET

NEBRASKA 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 of 1999 and in May 2000 the Nebraska Respite Network was funded by the state legislature and the Department of Health and Human Services was charged with administering the program to begin serving 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 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 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 typically every other month.
- Communication is through e-mails and teleconferencing. Nebraska is a large rural state with different services and needs. The Nebraska 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 deliver cookies and information about families in need of services to our legislators.
 - Coalition organizes 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 Care, Alzheimer's Disease, Hospice and Palliative Care.
- In 2004, NE Respite Coalition actively participates in "And Thou Shalt Honor" nationally televised PBS special including excerpts from the Caregiving Town Hall meeting filmed in Kearney, Nebraska.
- In 2006, Co-Sponsored National Respite Conference in Omaha, NE
- In 2007, Coalition initiates 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," results 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.
- Hosts Statewide, "Caring for Your Parents," Workshops.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Original bylaws
- 2010 strategic plan

State Contact Information:

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Jinx Hackler, Co-Chair
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Prepared in 2011 by the Nebraska Respite Coalition. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org.

STATE FACT SHEET

NEVADA LIFESPAN RESPITE CARE 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 and 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 AoA-funded Lifespan Respite Care Program grant awarded to the Nevada Aging and Disability Services Division will 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.

Meetings and Communication

- The Nevada Lifespan Respite Care Coalition holds 4-6 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.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- 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:

- Rique Robb, President, P.O. Box 2072, Sparks, NV 89432
- Susan Hirsch, Vice President, 888 Bonneville Ave., Las Vegas, NV 89106
- Jacqueline Ragin, Treasurer, 4505 Maryland Pkwy., Box 5019. Las Vegas, NV 89154
- Carol Meyer, Secretary, 890 Mill Street, Ste. 102, Reno, NV 89502

Key Contacts for the Nevada Lifespan Respite Care Program grant are:

- Vicki Puccinelli, Acting Program Manager, Aging & Disability Services Division, 3416 Goni Road, Ste. D-132, Carson City, NV 89706, 775-687-0561, vkpuccinelli@adsd.nv.gov
- Cheryl Dinnell, Lifespan Respite Care Program Coordinator, 890 Mill Street, Ste. 102, Reno, NV 89502, 775-337-2571, dinnelc@ccf.org



STATE FACT SHEET

NEW HAMPSHIRE COALITION (IN DEVELOPMENT)

Start-Up Process

- 2009 - NH 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. It was incorporated into the grant activities to develop a coalition.

Structure

- A Lifespan Respite Coalition Workgroup was created through recruitment of varied and diverse stakeholders.

Staff

- The Coalition Workgroup is coordinated and led by grant staff.

Funding

- Meetings and supplies of the workgroup are funded through the grant. The workgroup's responsibilities include exploring sustainability options, with funding being one of those issues to address.

Membership

- Recruitment for and participation in the Coalition Workgroup has included stakeholders from the grantee, NH Aging and Disability Resource Center (ADRC), NH state agencies providing community based care across the lifespan, the NH Family to Family Health Information Center, Mental Health agencies, condition specific advocacy groups (5-7) and caregivers.

Meetings and Communication

- The Lifespan Respite Coalition Workgroup meets monthly. The meetings incorporate the ability for participants to join by conference call.

- Communication includes updates on the grant as well as meeting notes and resource documents.

Major Activities

- The Vision and Mission have been completed for NH Respite Coalition using guidance from the workbook from ARCH National Resource Center "Building a Statewide Respite Coalition: Where Do We Begin?" The Advisory Planning Committee has accepted the vision: "The New Hampshire Lifespan Respite 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."
- They also accepted: "the mission of the NH Respite Coalition is to recruit and train a 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."
- The Coalition Workgroup has also created a Logic Model and created the framework for a statewide Needs Assessment.
- 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 Mission
 - Develop guidelines for Lifespan Respite Care Coalition

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Caregiver Needs Assessment
 - 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

- Statewide Lifespan Respite Summit
 - A day long summit held October 2011, with meeting sites around the state linked by videoconferencing. The purpose of the Summit was to bring together stakeholders and caregivers to further the development of the NH Lifespan Respite coalition as a working alliance between
 - family caregivers
 - those who work with & support family caregivers, and
 - stakeholder organizations

State Contact Information:

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STATE FACT SHEET

NEW JERSEY LIFESPAN RESPITE COALITION

Start-Up Process

- After New Jersey hosted the National Respite Conference in Atlantic City in September, 2004, the NJ Lifespan Respite Coalition was founded in 2005 to promote the pending Lifespan Respite Care Act.
- The Coalition was founded under the auspices of The Family Resource Network, a statewide non-profit provider and advocate for the population with Intellectual and Developmental Disabilities.
- In 2005 the Coalition held its first statewide meeting with the Coordinator of the National Respite Coalition to discuss the need and promote passage of the legislation.
- In 2006 the Coalition held a subsequent strategy meeting in Woodbridge with stakeholders and NJ Congressman Mike Ferguson, the prime House sponsor of the legislation.
- NJ Coalition representatives also testified in 2006 at several hearings held by the House Commerce Committee.
- In December 2006, after the Act was passed by Congress, the NJ Coalition was the only state coalition represented at the Oval Office signing.

Structure

- The Coalition has been a loose federation of agencies. The membership includes over 80 active participants.
- A committee is being formed to recommend membership guidelines and responsibilities, bylaws, policies.
- The Coalition will now be involved with the activities of the recently funded New Jersey Lifespan Respite Program.

Staff

- The Coalition does not have paid staff at this time. Senior staff of The Family Resource Network as well as the Coordinator of the NJ Lifespan Respite Program contribute time to the Coalition.

Funding

- Currently the Coalition's expenses are underwritten by The Family Resource Network. A committee is being formed to explore additional funding opportunities.
- With the recent funding of the New Jersey Lifespan Respite Program, there is a paid part time Coordinator who will contribute time to Coalition activities and coordination.

Membership

- Currently there are 80 "members", nearly all of which are non-profits serving the disability and chronic illness community.
- Caregivers and family members are also participating members of the Coalition.
- Outreach is underway to the aging community.

Meetings and Communication

- The Coalition meets bi-monthly in person and by conference call.
- Summit participants received synopsis of the Summit findings.
- The Coalition participated in a conference call to submit suggestions and recommendations for the Lifespan Respite application.
- The Coalition will participate in 2011 Summit and 2012 Respite Roundtables.

Major Activities

- Lifespan Respite Summit 2005
- Lifespan Respite Summit 2008
- Lifespan Respite Summit 2009 - produced notes summarizing barriers to receiving respite and suggestions for coordinated respite delivery system
- Developed "I Support Lifespan Respite" Facebook page 2009
- Utilized Summit findings to apply for Lifespan Respite Funding 2011 in partnership with Department of Human Services and Department of Health and Senior Services
- Awarded Lifespan Respite Project 2011
- Planning 2011 Summit and focus groups

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- None at this time

State Contact Information:

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Prepared in 2011 by the New Jersey Lifespan Respite Care Coalition. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org

STATEWIDE CAREGIVING & RESPITE COALITION OF NEW YORK

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 for 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 will be 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).”

Current Program Highlights:

- 2010 New York State received Lifespan Respite grant
- NY State and Lifespan of Greater Rochester entered into a partnership to manage the State Coalition and execute grant deliverables
- 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)

Staff

- NYSCRC shares staffing between New York State Office of the Aging (NYSOFA) and Lifespan of Greater Rochester. There is 1 dedicated FTE from Lifespan and grant management staff provided from NYSOFA.

Funding

- NYS Office for the Aging grant (2008-2010)
- Langeloth Foundation grant (2010-2011)
- Additional funding from the NY State Agency on Aging, which had successfully competed for a federal Lifespan Respite Grant

Membership

- NYSCRC currently has over 350 members.

Meetings and Communication

- Monthly e-news and advocacy alerts
- Annual November Caregiver Awareness Award Event
- Monthly best practices workshops via conference call

Major Activities

- In May 2009, a major conference was held to bring together all the major participating organizations in the state and to officially launch the Statewide Caregiving & Respite Coalition of New York. The conference featured substantive workgroup activity, informative discussions by national and other state respite advocates, and significant planning sessions.
- In November 2009, SCRCNY and the NYS Family Caregiver Council held a joint honorary luncheon and workshop. There were four award categories:

cross-generational caregiving, kinship care, aging services caregiving and disabilities services caregiving. Awardees were: ShareTheCare, Inc. of NYC; Catholic Charities Caregiver Support Services Kinship Caregiving Program, Albany, NY; Mercy Care for the Adirondacks, Lake Placid, NY; and Schenectady County Chapter, NYSARC in Schenectady, NY.

- The Coalition hosted the second annual Caregiving & Respite Awareness Honorary Event in November 2010 in conjunction with the NYS Family Caregiver Council.
- From March 2011- September NYSCRC and invited parties engaged in a "Think Group" process to determine how respite was going to be defined in NY thus providing a framework for the inventory process
- The Coalition underwent a new branding process which included a new name, logo and website
- NYSCRC's Statewide Inaugural Caregiver Conference will be held Nov. 17.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Brochure is available on coalition website: under construction
- Periodic Newsletter
- 2010 Caregiver & Respite Survey <http://www.scrny.org/advocacysurvey.pdf>

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Prepared in 2011 by the Statewide Caregiving & Respite Coalition of NY. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org

STATE FACT SHEET

NORTH CAROLINA RESPITE CARE COALITION

Start-Up Process

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

Structure

- The NCRCC is housed at a statewide nonprofit agency that functions as its fiscal agent. There is a board of directors and local leadership roles for each of three regions and chapters.

Staff

- A paid part-time Director and Coordinator manage the coalition while also serving in other capacities at the nonprofit agency.

Funding

- The NCRCC staff positions are funded by Easter Seals UCP North Carolina and VA, where the coalition is housed.
- Membership dues are paid on an annual basis and those dollars assist with supporting meetings and some supports for family members to travel and attend events.
- Fundraising through a silent auction at the state respite conference have supported respite for a number of families who had no other resources.

Membership

- Over 100 individuals actively participate statewide in the NCRCC. This participation covers three regions of the state and is growing with the inclusion of chapters.

Meetings and Communication

- Meetings are held in the regions on a quarterly basis. Local chapters meet between the quarterly meetings. There are two state meetings each year.

- The NCRCC hosts phone conferences to address topics and needs of the group and will host a webinar in 2011.
- The NCRCC communicates by website www.NorthCarolinaRespiteCareCoalition.org and by email on a regular basis.
- Mailings are provided for all meetings.
- Workdays are planned to address tasks as needed.

Major Activities

- Hosted several one-day respite conferences and respite awareness days
- Assist State Health Department with incorporation of respite as a benefit under the state's Children's Health Insurance Program
- 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
- Successful Active Membership Drive in all three regions of the state
- Starting NCRCC Local Chapters
- Website/Meeting minutes and up-to-date information with links to agencies
- Participated in State Respite Workgroup with focus on CMS respite definition
- Host program presentations to see the "Best of the Best"
- 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
- Collaboration with agencies across services, ages and focus
- Pilot Voucher Funding Program
- Activities related to Passage of the Lifespan Respite Care Act
- Sent parents to participate in Capitol Hill events in support of Lifespan Respite Care Act
- Partnership with NC Division of Aging in receipt and implementation of Lifespan Respite Program
- Participation in national respite conferences and networking/consulting with other states on lifespan respite issues

Documents Available (*Bylaws, Mission, Vision, Surveys, Brochures*)

- Bylaws
- Mission and Vision
- Event Planning Meeting Minutes
- State Conference Flyers
- Voucher information
- For more information, see website at www.northcarolinarespitecarecoalition.org/

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STATE FACT SHEET

OHIO RESPITE COALITION

Start-Up Process

- Using a small charter group of interested individuals and a grant from ARCH National Respite Network and other supporter funds, Ohio held a Respite Summit in March of 2011.
- Over 100 people attended, with participants including state agency representatives, family members, advocates for families, providers and other interested stakeholders.
- At the Summit, conveners asked people to sign up if they wanted to form a respite coalition in Ohio. This was the beginning of the Ohio Respite Coalition.

Structure

- The Ohio Respite Coalition functions as a volunteer collaborative, with members sharing in the work of the Coalition.
- The Steering Committee defines annual goals and assigns those goals to Coalition committees.
- The Membership committee works on recruitment and retention of members and communication with the coalition.
- The Stakeholder Education committee communicates with all stakeholders on the issues around respite. They also help coordinate regional respite summits that focus on expanding our knowledge of what is happening with respite services in Ohio.
- The Research Committee helps to collect data and research on respite.
- The Government Relations Committee assists in educating legislators and government stakeholders on respite issues and needs.

Staff

- There is no paid staff. Easter Seals provides organizational support through their Director of Public Affairs, with a small support stipend from the Lifespan Respite Act funds.

Funding

- Currently, the Ohio Respite Coalition is supported through the Lifespan Respite Act funds with in-kind support from Easter Seals.

Membership

- As of September 2011, there are 128 members of the Ohio Respite Coalition representing all geographic areas of Ohio, with a diverse mix of representation from families and caregivers, providers, state and local government, faith-based organizations and other stakeholders.

Meetings and Communication

- The Ohio Respite Coalition plans to hold an annual respite summit in the spring of each year.
- Regional summits are held depending on the interest and efforts of members in that region.
- Communication with the membership is through list serv email and a quarterly newsletter.

Major Activities

- The major activities of the Ohio Respite Coalition include an annual summit, regional summits, data collection on respite issues, assisting in the implementation of the Lifespan Respite Act Project, and communicating with the membership.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Facebook page: "Ohio Respite Coalition"

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STATE FACT SHEET

OKLAHOMA RESPITE RESOURCE NETWORK

Start-Up Process

- A Respite Task Force began meeting on August 29, 1997, with staff from the following state agencies and organizations: Department of Human Services (DHS) Family Support Services Division, Developmental Disabilities Services Division (DDSD), Division of Children & Family Services (DCFS), Office of Child Care (OCC), Oklahoma Health Care Authority (OHCA), Oklahoma's University Center for Excellence Center for Learning and Leadership (CLL), Developmental Disabilities Council, and Oklahoma Area-Wide Services Information System (OASIS). At this meeting, we adopted a lifespan vision statement and several goals to build an infrastructure to meet the respite needs of families in Oklahoma.
- The Respite Task Force became the Oklahoma Respite Resource Network (ORRN) on February 3, 1998.
- DDSD provided seed money of \$45,000 and within six months, two foundation grants provided a total of \$50,000.
- Subcommittees evaluated current respite payment rates of Oklahoma agencies and surveyed other states to determine a national average.
- Subcommittees developed a common respite application to ensure consistency in gathering data, determined eligibility requirements based on funding sources, and set the dollar amount of the respite voucher.
- ORRN researched feasibility of contracting with public and private agencies to put funds in a respite account and use DHS as the fiscal intermediary and worked with agency directors to commit funds to the respite voucher account.

Structure

- ORRN promotes the use of a voucher, which allows family caregivers to purchase respite supports from either an informal network or a formal service delivery system. Use of a voucher empowers caregivers by recognizing their decision-making capacities.
- Oklahoma Areawide Services Information System (OASIS) serves as ORRN's intake point by sending and receiving applications. DDSD and Aging fund two full-time respite coordinators at OASIS. OASIS forwards applications to DHS staff who approve and issue vouchers.

- Family caregivers may hire anyone they choose and set the rate of pay. Once respite has been provided, the vouchers are sent to OKDHS Finance for payment. The respite provider usually has a check within 7-12 days.

Staff

- ORRN serves as the State Lifespan Respite Program, although through its volunteer membership and activities, it carries out coalition activities as well. It is housed with the Oklahoma Area-Wide Services Information System (OASIS). OASIS sends and receives voucher applications and maintains a database of applicants. Oklahoma Department of Human Services Developmental Disabilities Services Division and Aging Services Division fund two slots at OASIS. All other staff are in-kind services from the funding sources.
- One of the co-chairs is the retired ORRN Director serving in a volunteer capacity.

Funding

- All of the funding for ORRN comes from redirected state and federal dollars. State dollars are from Developmental Disabilities Services Division and Aging Services Division. Federal dollars come from Maternal Child Health (Title V), Older Americans Act, Adoptions (Title IV-E), Children with Special Health Care Needs (Title V), SSI-Disabled Children's Program, TANF and Mental Health Systems of Care. In the beginning money from three private foundations assisted with gap funding for Traumatic Brain Injury and mental health issues.

Membership

- ORRN is a volunteer collaborative. There are no membership dues.
- There are currently 35 partners involved in ORRN including parents, foster parents, public and private agencies, and advocacy groups.

Meetings and Communication

- The ORRN meets four times a year.
- All members are on a mailing list to pass along alerts and information.

Major Activities

- The past three years, the focus has been to support the Oklahoma Olmstead Strategic Plan for people with disabilities and the aging population. Respite

was included in Oklahoma's plan. Educational materials were developed to educate legislators and policy makers on the need for respite. Development of lifespan support legislation (including respite care) was a priority 2008-2010.

- ORRN hosted the National Respite Conference in September 2005 in Oklahoma City.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Three surveys have been completed.
- ORRN Brochure
- ORRN history
- ORRN Goals and Objectives
- Website for voucher information
- Power Point Presentation on Coalition Building
- Power Point on ORRN

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STATE FACT SHEET

PENNSYLVANIA LIFESPAN RESPITE COALITION

Start-Up Process

- The Pennsylvania Lifespan Respite Coalition (PaLRC) has been active in the Commonwealth since 1998. The catalyst for the PaLRC's creation was the volume of calls to state, public and private agencies from family caregivers seeking respite services. These calls accounted for 1/3 of ALL calls to information, resource and referral lines throughout the state. In response to the requests for respite, the PaLRC formed to address a lack of respite options both in quantity and quality throughout Pennsylvania. Initial activities included:
 - Convening Regional Focus Groups in November 1998, by the State Department of Health Special Kids Network to explore interest in respite care and define next steps
 - Facilitating a PATH Strategic Plan in February 1999, to identify short term and long term goals, specific time frames, people to enroll, and activities to sustain the momentum
 - Identifying work groups to address specific issues
 - Conducting outreach to all other regions of the state
 - Hosting a kickoff event September 1999, to bring together all potential state stakeholders. Events at the State Capitol included a Legislative Awareness campaign with visits to each legislator, a legislative awareness breakfast and a meeting of all interested parties to outline future activities
 - Establishing a formal network and information sharing process
- The PaLRC successfully co hosted the National Respite Conference in Pittsburgh in 2002 with ARCH. In addition, the PaLRC supported the formation of several regional respite coalitions to focus on addressing local respite issues while playing a part in the larger state and national effort. The PaLRC's initial focus was on:
 - Addressing state and national respite issues
 - Facilitating educational events for legislators in the State Capital
 - Increasing awareness of caregiver relief issues for community partners and stakeholders
 - Joining with likeminded groups and efforts such as the Family Support Advisory Council
 - Acquiring funding to increase availability and accessibility of respite care
 - Celebrating the last week of September as Pennsylvania's Respite Awareness Week (first proclaimed by Governor Ridge in 2000, most recently proclaimed by Governor Corbett in 2011)

Structure

- A State wide coalition (PaLRC) open to caregivers, stakeholders, policy makers, provider agencies and community members
- A Yahoo group site to identify resources, problem solve and communicate to members
- Point of contact in each county
 - Assists caregivers address respite questions about availability, funding and access
 - Provide information to provider agencies about training opportunities
 - Assist in recruitment of paid and volunteer caregivers
 - Support legislators to address and respond to constituent requests for respite care
- Several regional coalitions under the umbrella of a State Coalition to address individual local area demands (formed between Spring 1999 - present)
 - Respite Provider for early childhood population
 - Respite Single Point of Contact & Resource Center as well as funding source
 - Provider forum for agencies to recruit caregivers, share training, respond to concerns
 - Networking group to address needs of rural communities
 - Grassroots network of parents and providers promoting legislative change
- Email list serve to providers, parents, organizations and interested community members
- Key seats on Pennsylvania committees designed to impact legislation, services and funding

Staff

- Volunteer Co-Chairs to disseminate information, field phone calls, serve on committees and call people together on a state level
- Some regions have (very) part time paid leadership and/or a volunteer Board of Directors, and / or paid respite providers
- No formal paid staff at the state coalition level
- Staff support from the Pennsylvania Department of Public Welfare, State United Cerebral Palsy, and University Center for Excellence co- facilitate bi monthly meetings, Summits and other statewide activities and initiatives

Funding

- No formal funding stream for State Coalition

- Activities of State Coalition supported by State Agencies (Department of Health, Department of Public Welfare, Developmental Disabilities Council) and Foundations or Organizations promoting values based work
- Regional coalitions obtain their own funding
 - One coalition operates as a 501(c)(3) non profit
 - One coalition is under the umbrella of a larger not for profit
 - Grant writing
 - Fundraising activities
 - Purchase of service or co-op care

Membership

- Members include respite agencies, non agency providers, related organizations, representatives from state initiatives and University centers, families and concerned citizens
- There is no fee for membership
- Agencies and individuals donate specific services, funding, or in kind time / resources to host events

Meetings and Communication

- Identified PaLRC leaders and members have been appointed to the advisory committee to steer the Federal Lifespan Respite Care Grant funding efforts
- Bimonthly meetings at the state Capitol (individuals can participate in person or via conference call)
- Regular meetings with state policy makers
- Regular email Communiqués
- Email/hard copy mail blasts to address legislative issues
- Conference calls
- Communicate and access to all documents via the Pennsylvania Respite Yahoo group site. This site is a membership site that allows individuals to post information, communicate with each other or have access to all products of the PLRC
- Regional meetings determined by local coalition
 - Monthly Board of Director/Advisory Council meetings
 - Quarterly gatherings of one or more coalitions
 - Fundraising activities

Major Activities

- The PaLRC sponsored its first awareness activity in 1999 with a Breakfast with the Legislators at the State Capitol. The day included a hot breakfast, a respected bi partisan speaker, stories by families. Over the years the PLRC

has hosted yearly small and large scale activities to commemorate Respite Awareness Week. They have also co sponsored two Statewide Respite Summits (details below). Other major activities have included:

- **Cookies and Milk with your State Legislator:** Regional forums gathering the grass roots efforts of local agencies and families. Utilizes donated coffee, cookies and milk from local vendors. Invited guests local, city, state and federal legislators who speak briefly and field questions from parents.
 - **Community Forums and Provider Fairs:** Held in different regions of the state (typically during Respite Care Awareness Week). Events include local media personalities with a connection to respite across age and disability and speakers who can provide information on providing care or identifying “outside of the box” respite. Each event is held in conjunction with a provider fair of services designed to help connect caregivers to or provide respite care in the region.
 - Active participation in state committees designed to create and support legislation and pilot programs that provide respite care or family support that are funded through state dollars
 - Regional collective advocacy workshops to educate, motivate and mobilize individuals and agencies interested in legislative change to promote respite care
 - **Give Families a Break** events designed throughout the year to raise awareness among Legislators, Health Care Providers, and the general public
 - Walk A Thon (Blue Cross/Blue Shield Health Insurance Provider’s “Walk for a Healthy Community”) to raise funds and awareness
 - **Friend Raisers:** Family Friendly events (miniature golf tournaments, concerts, craft shows)
 - Local and State Respite Awareness Proclamations
 - Awards for the outstanding individuals and communities impacting respite care
 - Co-sponsored **ARCH National Respite Conference** in August 2002 in Pittsburgh, PA
 - Optional participation in data collection to promote continuous quality improvement and data driven decision making.
 - Ongoing review of mission, focus and strategies by region
 - SWOT analysis
 - Non profit management clinic
- In November of 2007, Pennsylvania held the first of two Lifespan Respite Summits. The first summit was hosted by three statewide organizations with a deep investment in respite care issues. The day brought together 40 state department officials, policy administrators, statewide resource organizations and family advocates to meet with and learn from Jill Kagan, chair of the National Respite Coalition and program director of the ARCH National Respite Network and Resource Center. The 2007 Lifespan Respite Summit renewed enthusiasm to strengthen the PLRC’s statewide reach.

- After the summit a large group of committed stakeholders including caregivers, policy makers, providers and community members met regularly to focus on state respite issues. The group applied for and received support to host a second Lifespan Respite Summit, which was held in March of 2010. The day, hosted by several statewide community partners, was attended by twice as many stakeholders as the first summit and was again facilitated by Jill Kagan. The purpose of the 2010 summit was to develop collaborative working relationships among participating groups so that Pennsylvania could apply for a federal Lifespan Respite Grant. Equally important, was the group's goal is to maintain this collaboration when following through with the planning and implementation of a statewide Lifespan Respite Care system based on best practices consistent with the cross age / cross disability definition of respite care in the Federal Lifespan Respite Care Act (PL 109-442). The outcomes of the summits included:
 - Facilitating bi-monthly PLRC meetings in Harrisburg that can also be accessed by conference call for individuals throughout the Commonwealth
 - Establishing a Yahoo group site to bring together stakeholders, identify resources, problem solve and act on Federal issues that specifically effect respite care in Pennsylvania
 - Identifying an individual in each of Pennsylvania's 67 counties to serve as a point of contact for anyone seeking respite resources including legislators who are responding to constituent requests for respite care information
 - Supporting a formal statewide infrastructure that links funding streams and provider services to make it easier for caregivers to access respite services,
 - Increasing availability of lifespan respite training and resources to providers and caregivers
 - Improving the dissemination of information about lifespan respite programs
 - Constructing a collaborative relationship and building a bridge for communication statewide and regionally between the Aging Disability and Resource Centers, state programs, providers and PLRC

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- PATH strategic plan (year 1)
- Non Profit Clinic Assessment, Strategy Session and Goal Plan (year 7)
- Regional Brochure, Mission and Vision
- State Fliers
- Regional Website with database, downloadable forms for pre service and post service surveys, etc. (www.acrcc.org)
- Statewide Respite Resource guide

- Respite Summit (2007, 2010) notes, podcasts and follow up plans on Yahoo Group Site http://health.groups.yahoo.com/group/pennsylvania_respite/

State Contact Information:

To learn more about or join the PLRC contact MaryJo Alimena Caruso at 412.749.2863 or maryjo@thewatsoninstitute.org. You can also subscribe to the Yahoo group via email at pennsylvania_respite-subscribe@yahoogroups.com or by going to the site http://health.groups.yahoo.com/group/pennsylvania_respite/. Once the group site moderator approves membership, participants have access to all existing information as well as the ability to post questions, seek resources and participate in upcoming meetings.

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STATE FACT SHEET

THE CAREGIVER ALLIANCE OF RHODE ISLAND

Start-Up Process

2006

- 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.

2007

- Rhode Island Respite Coalition begins to meet monthly and educate state agencies, partners, and caregivers about the Lifespan Respite Act and planning advocacy agenda.

2008

- Rhode Island Respite Coalition becomes a member of the National Respite Coalition.

2009

- 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 our 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 works 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 need of respite care and working in partnership with the RI Lifespan Grant leadership to implement the goals and objectives of the grant to increase public awareness of respite, increase access to respite and coordinated service delivery across the lifespan, and grow the development and sustainability of the Rhode Island TimeBanks volunteer respite program.

Staff

- The Lifespan Respite Project Coordinator and TimeBanks Respite Program Coordinator who are funded by the Rhode Island Lifespan respite grant and employed by Parent Support Network of Rhode Island are assigned to provide ongoing leadership and coordination of the Caregiver Alliance. The Lifespan Respite Project Coordinator originated the Rhode Island Respite Coalition and continues to provide leadership with the Alliance and the Lifespan Respite Grant.

Funding

- The RI Lifespan Respite Project is dedicated to providing ongoing participant supports for Caregiver Alliance meetings and activities. Currently, the Lifespan Respite Grant is the only source of funding.

Membership

- The Caregiver Alliance has over 150 partners on our mailing list and we average 50 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 ages and disabilities.

Meetings and Communication

- The Caregiver Alliance meets every six weeks. Meeting announcements minutes are sent out in advance and are posted on the Rhode Island TimeBanks website. The Caregiver Alliance is in the process of creating its own website, E-Bulletin, and Facebook page.

Major Activities

- 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.
- Provided input in the development and implementation of the TimeBanks respite training and volunteer respite program.
- Continues to advocate at state policy meetings in regard 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.

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STATE FACT SHEET

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 US 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 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. The By-laws have a provision for a non-voting advisory committee to ideally represent more constituencies than the Board can encompass.
- A subcommittee of Board members, Advisory Committee members and non-member respite provider organizations and faith-based organizations plans and holds the annual Respite Solutions conference.

Staff

- In 2000, the SCRC began with a full-time Executive Director who continued through 2008. With reduced funding, the Executive Director is now part-time (and sometimes volunteer).

- A part-time Project Coordinator was recently hired to work on the Lifespan Respite Project.

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 – 2012) for the SCRC is through the Lt. Governor's Office on Aging, which received a federal Lifespan Respite grant. The SCRC is a partner in the implementation of the Lifespan Respite grant.

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, Advisory Committee, sub-committees, annual conference, email alerts and website.
- A majority of the Board are current or former caregivers. The Advisory Committee 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
- Respite Awareness Days at state capitol to inform legislators and increase awareness.
- Monthly partners meeting and Quarterly meeting of the Statewide Advisory Committee for the Lifespan Respite project.

Major Activities

- Annual Respite Solutions for the Faith Community conference attended by approximately 125 people.
- Advocacy, increasing awareness about the needs for respite and increasing respite options for family caregivers.

- Updating and expanding information available through our website:
www.screpitecoalition.org
- Collaborating with other agencies, organizations and family caregivers to establish a coordinated lifespan respite system in SC.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- A mission statement: The mission of the SC Respite Coalition is to expand quality respite opportunities in SC throughout the lifespan for South Carolina families who have a member with special needs. The Coalition's goals are to:
 - Educate the general public and specific groups about the need for respite care.
 - Develop strategies to provide and improve respite services for families.
 - Provide support for families and providers through a coordinated information resources.
- "What you Need to Know About Me" A Notebook for Family Caregivers
- Brochures and By-laws
- Most SCRC products are available through the website at:
www.screpitecoalition.org, which also provides links to other resources in SC and across the country.

State Contact Information:

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Prepared in 2011 by the South Carolina Respite Coalition. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org



STATE FACT SHEET

TENNESSEE RESPITE COALITION

Start-Up Process

- In the early 1990s, one state agency 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.
- Prior to funding, a small group focused on awareness and grant writing (to fund future efforts).
- Once funded with a full time coordinator, the TRC began establishing regional groups. Seven regional groups across the state were formed. Volunteers led the groups as chairs co-chairs. The coordinator was able to travel to the regions to motivate and organize the groups.
- Newsletters and other communications were distributed to keep the group cohesive.
- Once the regional coalition groups were established and the group had grown to over 1000 members and the coalition building funding was exhausted, the TRC became a 501(c)(3) nonprofit agency.
- Currently, a board of directors votes on fiscal, operational, and programmatic decisions.

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. Program staff (currently 5) has been added as the TRC has grown.

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 3 years and were allowed to carry over into the 4th year.
- Once the initial grant funding was exhausted, the TRC became a nonprofit agency so that it could solicit funding through grants and private donations. The advantage of this move was being able to be tax exempt and offer private donors tax deductions. Further, many foundations require the 501(c)(3) status for funding consideration.
- Current funding includes state grants, private foundation grants, private donations through annual campaigns and memorials, and funds collected through events.
- Fundraisers include: Jazzin for Respite, 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 comprises over 200 member agencies that provide information and assistance to caregiving families. The member agencies meet regularly to assess community needs, identify gaps in service, organize awareness events, coordinate funding support, and share information all for the benefit of families in crisis. Members include diverse representation from medical professionals, social workers, legislators, caregivers, service providers, and teachers. The TRC covers the lifespan and disability span.
- The TRC does not require dues at this time to be a member and is not considered to be a "Member" organization regarding its 501(c)(3) status.
- Membership is based on interest level. A person has to be interested and invested in Respite to become a member. Two levels of membership exist:
 - Active status means that a person is willing to participate in meetings, events, legislative advocacy, and member recruitment.

- Supportive status means that a person is willing to help with advocacy and member recruitment, but can't necessarily make meetings or events. Often supportive members are caregivers that need Respite or agency staff where one designated person is an active member.
- Members were and are recruited by other members. During the coalition-building period, regional contests helped boost membership.
- Membership is retained by maintaining communication, offering services to families that members are connected with, by planning events in regions, and being respectful of members' contact information and time constraints (many have full time jobs).

Meetings and Communication

- Regional coalition meetings are held throughout the state. While the coalition was being built, meetings were often monthly. Since becoming a 501(c)(3), the TRC groups have meetings when they have activities or need planning time. Some groups meet quarterly, some monthly, some bi-monthly.
- At the inception of the TRC, statewide meetings were held quarterly but are less frequent now. 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.
- Marketing materials are always available for members to spread the word about Respite.
- Newsletters were done monthly during coalition building. The TRC has varied in the frequency of newsletters from monthly to quarterly and now back to monthly.
- Website –It has been through several incarnations, with several volunteers, and currently is operating effectively. A new version with more interactive features is in development.

Major Activities

- Most recently, the TRC was named the partner organization for the Senior Companion Program in Davidson County. This program sponsored by the Corporation for National and Community Service will allow the TRC to expand the number of caregivers receiving respite.
- The TRC has partnered with the Tennessee Commission on Aging and Disability to implement a three-year federally funded Lifespan Respite Grant in collaboration with the Aging and Disability Resource Center.

- All regions participate in National Family Caregiver Month activities in November. Some of the activities include: family caregiver pamper days, legislative activities, banquets, media coverage, family caregiver gifts, etc.
- Other activities include fundraisers as mentioned above, but also smaller fundraisers on a regional basis – cell phone and ink cartridge recycling, bake sale, yard sale, and concession stands.
- Advocacy and Awareness, and Legislative activities – letters, phone calls, video messages, petitions, etc.
- Lifespan Respite Summit: 1st one in 2006
- Family directed respite: TRC provides over 200 families with vouchers for an array of direct services thereby empowering families to be in control of their caregiving responsibilities.
- Volunteer Respite: Working with universities and community volunteers, TRC delivered over 9,000 volunteer hours of respite last year.
- Helpline: A toll free number for families and professionals that provides guidance, information and assistance. TRC pledges to secure services for each family that calls. Calls have increased from 115 in a year to 700 last year.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Bylaws
- Surveys of caregivers (2)
- Surveys of professionals
- Membership forms
- Committee descriptions
- Program policies
- Volunteer program model and materials
- Marketing collateral
- Newsletters
- Video: *Portraits in Caregiving* – This short film profiles two caregivers and illustrates the type of support TRC offers to help them meet their daily challenges. <http://tnrespite.org/node/32>
- Website www.tnrespite.org

State Contact Information:

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STATE FACT SHEET

TEXAS RESPITE COALITION

Start-Up Process

- The Texas Respite Resource Network (TRRN) was formed in the late 1980s and functioned as the State clearinghouse and technical assistance network for respite in Texas, and later as staff to the ARCH National Respite Resource Center. It also functioned in the 1990s as the Texas Respite Coalition to provide input to the state about the delegation of nurse tasks in the provision of in-home services and other respite policy issues.
- In July of 2009, the Texas Department of Aging and Disability Services (DADS) invited previous members of the TRRN and other area agencies involved in respite within the state of Texas to become a member of the newly formed Texas Respite Coalition (TRC).

Structure

- Each member organization is formally represented by two spokespersons, one of which serves as the primary delegate for Coalition meetings and business and as the chief contact with DADS.
- Currently, the TRC has three standing work groups that act in an advisory capacity on issues affecting the coalition: Outreach & Awareness, Respite Inventory Planning, and Resource Development. Membership in the work groups is voluntary and meetings are conducted in the course of the TRC quarterly meetings.

Staff

- Although the TRC has no dedicated staff, it is supported by the Texas Respite Coordination Center (TRCC) project coordinator and DADS staff.

Funding

- Through funds received from grants, DADS supports both the cost of meetings and the travel expenses of members who incur them in order to attend the meetings.

Membership

- The Coalition currently consists of 38 member organizations including service providers, non-profit agencies, faith-based organizations, caregivers, and representatives of relevant state agencies. The Coalition stands ready to assist DADS in its efforts to coordinate the accessibility and availability of respite care for Texas family caregivers.
- Currently, there are no eligibility requirements or fees necessary to become a member.

Meetings and Communication

- The TRC holds quarterly meetings in the Austin area, with the option for members to participate via conference call.

Major Activities

- The first initiative addressed by the Coalition was to assist DADS in creating a Lifespan Respite Care Program. In 2009, the 81st Texas Legislature enacted two laws affecting respite care for caregivers in Texas: Senate Bill 271 and House Bill 802. SB 271 directed DADS to coordinate public awareness outreach efforts regarding the role of informal caregivers in long-term care. HB 802 appropriated \$1,000,000 over the Fiscal Year 2010-2011 biennium and directed DADS to create a lifespan respite services program.
- DADS applied for and received \$200,000 in grant funds from the U.S. Administration on Aging (AoA) to enhance and expand the coordination and availability of respite services in Texas, and to establish the Texas Respite Coordination Center. The Coalition has become an advocate in partnership with DADS for the Lifespan Respite Care Program, and the two have signed a memorandum of understanding that clearly supports the goal to enhance and expand the coordination and availability of respite services in Texas.
- The Coalition is working in conjunction with the TRCC to design and compile a comprehensive respite care inventory for the State of Texas. The inventory will include an exhaustive list of respite care providers and resources for caregivers and will be readily accessible to the public through a new respite-centered website as well as pre-existing public resources like Texas 2-1-1, a toll-free phone line that allows Texans to get referrals for a variety of public services. The Coalition is also collaborating with the TRCC on a statewide awareness campaign that will include media kits and public messages aimed at caregivers across the state.

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Memorandum of Understanding between the Texas Department of Aging and Disability Services and the Texas Respite Coalition
- TRC Charter

State Contact Information:

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Prepared in 2011 by the TX Lifespan Respite Program, Texas Department of Aging and Disability Services. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org

STATE FACT SHEET

VIRGINIA CAREGIVER COALITION

Start-Up Process

- The Virginia Caregiver Coalition (VCC) was formed in 2004 with an informal group of 22 professionals primarily focused on older adults who attended a coalition building training sponsored by AARP.
- Currently there are more than 85 members in the statewide coalition with a solid committee structure and representation of many ages, disabilities, and chronic conditions.

Structure

- The VCC is housed at the Virginia Department for the Aging (VDA) in Richmond, VA, which serves as the fiscal agent.
- The VCC is governed by an Executive Committee consisting of Chair, Vice Chair, Secretary, Founding Member, and Co-Chairs of the Standing Committees.
- The Standing Committees include: Education and Programming; Membership; Advocacy; and Finance.

Staff

- There are no paid staff positions at the VCC; however, there is extensive support from the VDA Program Coordinator who is responsible for administration of the National Family Caregiver Support Program and the Lifespan Respite Care Grant.

Funding

- The VCC has received limited funding through the VDA Program Coordinator participating in various National Alliance for Caregiving Projects and from the VDA administered 2025 Project.
- The VDA has provided administrative and videoconferencing support for the VCC.

Membership

- There is no membership fee to join and members represent numerous agencies and organizations as well as consumers and families throughout the Commonwealth
- Founding members of the VCC are those individuals trained by the AARP to form the VCC.
- Membership consists of volunteers dedicated to the mission and goals of the VCC.
- All members are required to complete a formal membership form indicating their willingness to serve as a member of the VCC and their interest in participating in Standing Committees.

Meetings and Communication

- Full member meetings are held bi-monthly and are announced through flyers via email networks.
- The VDA makes video-conferencing technology available in Richmond which allows members throughout the state to participate at a local site (e.g., health dept, area agency on aging). Members who cannot participate via local sites may participate at VDA or by teleconference.
- Typical meeting attendance ranges from 40 to 65 members and guests. Meetings generally last 2.5 to 3 hours and include a business portion as well as a featured key speaker on a topic requested by the VCC and arranged by the Education and Programming Committee.
- Meetings are open to the public and allow for announcements of upcoming events and meetings related to the work of the VCC.
- The Executive Committee meets bi-monthly, generally by teleconference, on the opposite months of full member meetings. The Standing Committees generally meet every other month.

Major Activities

- Ongoing: Support and promote the events of members and their agencies throughout the state (e.g., regional conferences, respite programs and events for caregivers)
- Various trainings held during the coalition's six year history.
- Presentation about the Coalition at the 2009 NCOA/AAA Annual Conference
- Every November: Special recognition of National Family Caregiver's Month

- November 2010: First time the VCC was recognized in the Governor's Proclamation of Family Caregiver's Month
- March 2011: First Virginia Lifespan Respite Summit
- Partnership with VDA to develop the Lifespan Respite Care Grant in Virginia

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- *Bylaws, Policies & Guidelines (last revised 2010)*: available in hard copy
- *Membership Form*: available in electronic copy
- *Meeting Flyers*: available in electronic copy
- *Caregiver Resource Manual (revised)*: available in electronic copy (Virginia Department for the Aging)
- *A Practical Guide to Respite for Your Family (1996)*: available in hard or electronic copy (Partnership for People with Disabilities, Virginia Commonwealth University)
- List of Meeting/Program Topics
- The Virginia Caregiver Coalition is dedicated to improving the caregiving experience through education, advocacy and resource accessibility so that caregivers are valued and supported.

State Contact Information:

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Prepared in 2011 by the Virginia Caregiver Coalition. For more information, contact Jill Kagan, ARCH, at 4016 Oxford Street, Annandale, VA 22003; (703) 256-2084; jbkagan@verizon.net. ARCH Website: www.archrespite.org



STATE FACT SHEET

RESPIRE & CRISIS CARE COALITION OF WASHINGTON

Start-Up Process

- The Respite and Crisis Care Coalition of Washington (RCCCWA) started with a two-day statewide conference funded by the state in 2003.
- Funding continued with a planning grant from the Paul G. Allen Family Foundation.
- The ARC of King County committed to fund a part-time staff person and the Paul Allen Grant supported that for some time.
- After the Paul Allen Grant ended, The Arc of King County continued to offer part-time staff support.

Structure

- The Arc of King County is a 501 (c)(3), the fiscal agent for the coalition, has a Board of Directors composed of parents of children with developmental disabilities, adults with developmental disabilities, and a variety of ethnic group representation.
- The Respite and Crisis Care Coalition of Washington is a statewide coalition.

Staff

- The Director of Outreach and Advocacy provides oversight for the Coalition while the Lifespan Respite Project Coordinator tends to coalition development and respite resource needs. The Arc facilitates regular meetings of the RCCCWA.
- Professionals from various interested social service agencies, government representatives, or caregivers themselves, are invited to attend meetings. They provide information and assistance to develop strategic planning that furthers the RCCCWA's mission.

Funding

- Currently (2010 – 2013) the RCCCWA has three-year federal funding for its Lifespan Respite Project from the Administration on Aging, channeled through Washington State's Department of Social & Health Services (DSHS),

Aging & Disability Services Administration (ADSA). The federal grant provides respite, coalition-building, and staff support.

- In-kind and direct grantee support is devoted to the Lifespan Respite Project by the following organizations:
 - Aging & Disability Resource Center in Pierce County;
 - Catholic Community Services (Volunteer CHORE Services program);
 - Girl Scouts of Western Washington;
 - The Arc of King County; and the
 - Washington State Child Care Resource & Referral Network.

Membership

- Currently, RCCCWA has over 150 members, including family caregivers. Continued future expansion is planned to cover a wider geographical and cultural membership. Both public and private agencies are involved. The core group members include:
 - Aging and Disability Services Administration/State Unit on Aging/Department of Social and Health Services (DSHS)
 - Catholic Community Services of Western WA-Volunteer Chore Services
 - Children's Administration/Foster and Kinship Care/DSHS
 - Crisis Clinic/King County - Caregiver Program
 - Economic Services Administration/Policy/DSHS
 - Girl Scouts of Western Washington
 - King County Kinship Collaboration
 - Kinship Caregiver (and former Director of Childhaven Crisis Nursery)
 - National Multiple Sclerosis Society-Greater Northwest Chapter
 - Pierce County Aging and Long Term Care-Aging and Disability Resource Center
 - Senior Services of Seattle King County-Family Caregiver Support Program
 - The Arc of King County
 - WA State Child Care Resource and Referral Network
- There are no membership fees or dues currently.

Meetings and Communication

- In the first half of 2010, the RCCCWA held monthly meetings during the process of strategic planning for the federal Lifespan Respite Grant. Quarterly coalition meetings beginning Winter 2011 have occurred in both western and central Washington State.

Major Activities

- Developed and implemented Lifespan Respite statewide needs survey via internet
- Conducted seven focus groups across the state based on the survey results
- Developed a model countywide lifespan respite directory for King County
- Developed a statewide lifespan respite approach in relation to the 2010 Lifespan Respite Grant application
- Assisted the state in successfully applying for the FY 2010 Lifespan Respite Grant from the Administration on Aging, US Dept. of Health and Human Services

Documents/Resources Available (Bylaws, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies)

- Statewide survey
- King County resource directory
- Webpage (under construction)
- PowerPoint

State Contact Information:

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STATE FACT SHEET

RESPITE CARE ASSOCIATION OF WISCONSIN

Start-Up Process

- In 1999, Wisconsin adopted 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.
- In 2010, Wisconsin was awarded a Federal Lifespan Respite grant. The Wisconsin Department of Health Services, which is the grantee of record, contracted with RCAW to administer the program in partnership with Easter Seals Wisconsin.

Structure

- A 10-person board of directors oversees the program, which is staffed by a full-time Executive Director and a ¾ time Project Coordinator.
- RCAW contracts with 5 regional projects to implement the Wisconsin Lifespan Respite program, contracts with another 5 regional projects to implement the Child Abuse Prevention program, and contracts with Easter Seals Wisconsin to partner in implementing the Federal Lifespan Respite program.

Staff

- Staffing consists of a full-time Executive Director and a ¾ time Project Coordinator.

Funding

- RCAW is funded by state general purpose revenue through the Wisconsin Department of Health Services for the WI Lifespan Respite program, by state general purpose revenue and program revenue through Wisconsin Children's Trust Fund for the Child Abuse Prevention program, and by Federal revenue through the Administration on Aging for 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.

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, Strategic Plans, Surveys, Brochures, Registries, Webpage, Need Assessments, Forms, Policies*)

- Bylaws, Project Workplans, Brochure, Website at www.respitecarewi.org, Policies, and Newsletters.

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